

Disclosure of Disease among Women affected by Leprosy: A Qualitative Study

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ABSTRACT

Purpose: *Although leprosy is completely curable with multidrug therapy, it is unfortunate that the stigma attached to leprosy persists even today. Fear of social exclusion prevents disclosure of the disease to the family and community. This study aimed to evaluate the extent of disclosure of disease among women affected by leprosy in a tertiary referral hospital in Chhattisgarh State, India.*

Method: *A qualitative study was conducted with 57 women affected by leprosy who reported at a tertiary referral hospital in Champa, Chhattisgarh State. The respondents were 18 years of age or older, and had completed multidrug therapy for leprosy. They were asked whether the disclosure of disease had affected their interactions with family, neighbours and community members.*

Results: *Of the 57 women, 48 (84%) had disclosed their disease to their family, 17 (30%) to their neighbours and 13 (23%) to the community members. Thirty women (53%) reported that they experienced problems after revealing the ailment to their family, friends and neighbours. The qualitative analysis found that negative behaviour towards people affected by leprosy still persists in the community. Consequently, women affected by leprosy try to hide their disease due to fear of negative community reactions.*

Conclusion: *This study emphasises the need to spread awareness about the disease and its transmission, by educating the people affected by leprosy, their families and the community. This should be a continuous process in order to reduce or remove the stigma and discrimination against women affected by leprosy, in particular.*

Key words: *leprosy, disclosure, women, stigma, Champa*

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INTRODUCTION

Today leprosy is curable with multidrug therapy (MDT) (WHO study group, 1982). Unfortunately, the stigma attached to leprosy still persists (Kaur and Ramesh, 1994; Scott, 2000) and it remains a problem in several countries, particularly in India (Noriega et al, 2016). Society maintains negative feelings toward people with leprosy (Singh, 2012). Perception of stigma and experiences of discrimination cause people to feel ashamed, and may lead them to isolate themselves from society, thus perpetuating the stereotype that leprosy is something shameful to be hidden (Arole et al, 2002). This may cause anxiety, depression, isolation, problems in family relationships and friendships, also in reduced treatment adherence and retaining responsibilities in family life. In communities of many developing countries, the real situation of people affected by leprosy is often characterised by extreme dependency and discrimination in every aspect of their lives (Rao et al, 1996).

Women with leprosy encounter many problems in daily life, mainly due to stigma (Sarkar and Pradhan, 2016). Women with disabilities are often beaten or abused (Disabled World, 2018). Peters et al (2014) observed that the women who had concealed their illnesses were the ones who most frequently reported feelings of fear, sadness, shame, low self-esteem and depression, and that these feelings often resulted in self-isolation. Besides, women affected by leprosy experience more fear of the disease than the men affected by leprosy (Govindharaj et al, 2018). Out of fear of infecting family members, affected women keep themselves aloof and are constantly worried about their marriage prospects or, if married, about divorce and separation. Fear of social ostracism prevents them from disclosure of the disease to the community (Kaur and Ramesh, 1994). The major cause for late diagnosis of leprosy in women is the fear of stigma and being ostracized by family and community (Varkevisser et al, 2009).

Aim

This study aimed to evaluate the challenges regarding disclosure of disease among the women affected by leprosy in a tertiary referral hospital at Champa in Chhattisgarh State, India.

METHOD

Study Setting

A qualitative study was conducted from March to June 2016 at a tertiary leprosy referral hospital in Champa, Chhattisgarh State.

Study Sample

The participants were 57 women, aged 18 years and above, who had completed their multi-drug therapy (MDT). Informed consent was obtained from each individual and the interview was conducted in privacy. Confidentiality was maintained throughout the study.

Study Tool

A semi-structured questionnaire was used to record the demographic and disease profile of the women. They were asked questions about disclosure of their disease in order to know whether the disclosure affects their participation among family, neighbours and community members.

Ethics Approval

The study proposal was approved by the Allagappa University, in Tamil Nadu, India.

Permission to conduct the study was obtained from the superintendent of Bethesda Leprosy Mission Hospital.

RESULTS

Demographic Profile

Of the 57 women, 20 (35%) were between 18 and 30 years of age, 88% were married and 51% were illiterate. Nearly half of them (45%) were housewives and 84% had family income below Rs 5000 (Indian currency) (shown in Table1).

Table 1: Demographic Profile of the Participants (n=57)

Variables	Frequency	Percent (%)
Age		
18 – 30	20	35%
31 – 60	37	65%
Marital Status		
Married	50	88%
Single	7	12%
Education		
Primary & Secondary	20	35%
Higher Secondary & above	8	14%
Illiterate	29	51%
Occupation		
Housewife	26	45%
Farmer	11	19%
Labourer	14	25%
Student	6	11%
Family Income per month		
Up to Rs.5000	48	84%
Above Rs.5000	9	16%

Disease Profile

About three-fourths (74%) of the affected women were diagnosed as multibacillary disease and 23% had grade 2 disability. Nearly half of them (44%) had been released from treatment (RFT) for more than 2 years, and 30% came to the hospital for illness due to leprosy (shown in Table 2).

Table 2: Disease Profile of the Participants (n=57)

Variables	Frequency	Percent (%)
WHO Classification		
Multibacillary (MB)	42	74%
Paucibacillary (PB)	15	26%
WHO Disability Grade		
Grade 0	32	56%
Grade 1	12	21%
Grade 2	13	23%
Release From Treatment (RFT)		

0- 2 years	32	56%
3- 4 years	15	26%
Above 4 years	10	18%
Reason for visit to Hospital		
Follow-up	25	44%
Leprosy Complaint	17	30%
Non-Leprosy Complaint	15	26%

Disclosure of Disease

Among the 57 participants, 48 (84%) had disclosed their disease to their family, 17 (30%) had disclosed it to their neighbours and 13 (23%) had disclosed it to the community members (shown in Table 3).

Table 3: Disclosure of Disease by the Participants (n=57)

Disclosure of Disease	Frequency	Percent (%)
Family		
Disclosed	48	84%
Not Disclosed	9	16%
Neighbours		
Disclosed	17	30%
Not Disclosed	40	70%
Community		
Disclosed	13	23%
Not Disclosed	44	77%

Factors affecting Disclosure of Disease

The findings that were identified and emerged through analysis of qualitative data concerning disclosure of disease were: fear of disease, positive experience after disclosure, violent reaction after disclosure, psychological issues, self-stigma, problems in practicing self-care, stigmatisation and family members, beliefs and myths attached to leprosy, experience of social stigma, and employment issues.

a) Fear of the disease

An 18-year-old female college student who had a claw hand deformity said,

“I feel afraid if my friends come to know, they will gossip about my health condition and ignore me; also, I lack interest in my studies.”

b) Positive experience after disclosure

Twenty-seven (27) women (47%) reported that they did not have any problem due to the disease and also that there was no discrimination and stigmatising attitude in their village. A 39-year-old woman reported that people already knew that she was affected by leprosy because of her hospitalisation. However, she did not face any stigmatising attitude from people in her village.

A few women had made the disclosure themselves, while a few were identified by others due to their visible physical deformities. A 27-year-old woman had completed her MDT 10 years earlier. She had developed self-confidence after completing her treatment and was ready to face any problems which might arise due to leprosy.

A 48-year-old woman without a physical disability, who was treated 6 years previously, said,

“In my village, all the community members are aware that I have been treated for leprosy, but still there wasn’t any problem with me. I as usual participate in all the social activities and my neighbours come to my home just like before.”

Another 35-year-old woman without a physical disability, who was treated 2 years earlier, said,

“In my village all of them know I was affected by leprosy, and we are all living together without any problem.”

A 30-year-old woman with an ulcer on her right foot said,

“Due to ulcer on my foot, most of my neighbours know I was affected by leprosy, but they never neglected me. I myself feel inferior and avoid participating in social activities and functions in my village.”

c) Violent reaction after disclosure

Women affected by leprosy are sometimes abandoned by their husbands. In this study, a

41-year-old woman who had no disability and was treated 10 years earlier said,

“My husband called me as a leper and abused me whenever he had alcohol. He even rejected and did not support me get treatment in the early disease period (early stages of the disease).”

d) Psychological issues

One 32-year-old woman did not disclose the disease to anyone but felt ashamed and isolated herself.

Another 33-year-old woman said,

“I was very upset and depressed and had suicidal thoughts many times due to this disease. Nowadays I get unnecessarily stressed and afraid to tell anyone.”

A 40-year-old woman who underwent treatment 5 years ago said,

“Due to the visibility of patches on my face and hand, all of them came to know I was affected with leprosy. But myself getting angry and frustrated to live, asked myself, Why me? What sin have I committed?”

e) Self-stigma

A 53-year-old woman said that some people affected by leprosy are already living in the same village. When looking for a bride for her son, her family was not willing to find someone from the general community because of fear of stigma and discrimination. For this reason, preference was given to a family with a history of leprosy.

Another woman, 50 years of age, who was treated for leprosy 6 years earlier, said,

“By God’s grace, I have only patches in my body which are not visible to others. If I had any signs and physical deformities, people may easily identify and discriminate me.”

f) Problems in practicing self-care

A 35-year-old woman had anaesthetic foot and used to avoid using micro-cellular rubber (MCR) footwear in her village due to fear of stigma and discrimination.

Another 50-year-old woman with anaesthetic foot, living in a joint family, disclosed her health status only to her husband and children, but the rest of the family members were not aware of it. If they had known that she was affected by leprosy, there were chances that her family would be isolated from the other family members. Hence, she avoided wearing MCR footwear.

g) Stigmatisation and family members

A 27-year-old woman who had recently completed treatment said that she always came with her father to collect medicines. She had not disclosed the disease status to her husband and in-laws due to fear of divorce. Another 25-year-old woman also revealed that she never wanted to disclose her health status to her husband and in-laws for fear of divorce. She could not imagine herself as a divorced woman, so only her parents knew about her health condition.

h) Beliefs and myths attached to leprosy

A 52-year-old woman, who had received MDT ten years previously, believed that if her enemies came to know that she had been affected by leprosy, they could easily send evil spirits towards her and her family.

i) Experience of societal stigma

A 32-year-old woman, treated for leprosy 10 years before her marriage, said,

“When I started to come to the hospital for leprosy care, I came to know that there are some people from my village who are already affected with leprosy, and so the community members have separated and sent them to the nearby leprosy colonies, so I started to hide about my health condition to my husband and my in-laws.”

A 30-year-old married woman, who had been given MDT two years earlier, said,

“Only my husband knows about my disease status and I fear to disclose it to my remaining family members, because I had an experience in my village about 10 years ago. There was an old lady diagnosed with leprosy, so the community members isolated her in a nearby farm; after a few months the lady died, without any help from others.”

A 32-year-old woman, treated with MDT two years previously, experienced stigmatization from the community in her village. People identified that she was affected with leprosy by the visible skin patches on her body. Whenever she used to go to bath in the pond, people used to keep a safe distance and gossip about her among themselves.

j) Employment issues

A 31-year-old woman was a Panchayat member in her village. She had completed MDT about 3 years earlier but feared disqualification from her post if community members should come to know that she had been affected by leprosy.

DISCUSSION

This study attempted to identify the factors affecting disclosure of disease among women affected by leprosy. The study observed that 30 women (53%) had problems resulting from disclosure of the disease to their family, friends and neighbours.

The fear of leprosy leads to stigma and discrimination. This is due to lack of understanding and knowledge about leprosy, which increases misconceptions about the disease transmission and treatment (Navon, 1998). Fear of social ostracism prevents the disclosure of disease to the spouse, family members, relatives or friends (Thilakavathi et al, 2012) and also to the community (Kaur and Ramesh, 1994). In this study, nine (16%) of the participants did not disclose the disease status to their family due to fear of stigmatisation, and forty (70%) of them did not disclose the disease status to their neighbours and community.

Due to the stigma of leprosy many communities and children find themselves ostracised, and children are bullied by their classmates and isolate themselves. They want to play with their friends but are pushed away (Uniting to Combat NTDS, 2018). A study from Nepal reported that younger people who develop leprosy may find that it restricts their education (Stigter et al, 2000). The current study also found that a female college student with claw hand deformity due to leprosy was afraid of separation from her friends.

This study observed that half of the women did not have any problem due to the disease; also, their family members, friends and neighbours were more supportive. However, a few women imposed restrictions on themselves and avoided participation in social activities, even though they had a positive environment after disclosure of disease. Lusli et al (2016) reported that the family or community members who know that someone around them is affected by leprosy might want to care for, show kindness and support the person, but more often people are worried about infection and tend to distance themselves.

Women are treated worse if they have leprosy than men and are already dependent on others for their living (Try, 2006). Male dominance in society and

the household, in decision making, and income generation is a socio-cultural factor that gives men more respect than women even if they become stigmatised due to leprosy (Try, 2006). A study from Nepal (van't Noordende et al, 2016) found that women affected with leprosy reported sexual and alcohol-related emotional and physical abuse by their husbands. Women affected by leprosy are sometimes abandoned by their husbands. This study also found that a 41-year-old woman, who underwent treatment 10 years ago, was verbally abused by her husband and did not get any support during her treatment (MDT) period.

Depression and anxiety are some of the serious issues among leprosy-affected persons (Scott, 2000; Tsutsumi et al, 2004; Lepra, 2018; Ramasamy et al, 2018). Society's negative attitude towards women is magnified when there are visible signs of leprosy (van'tNoordende et al, 2016). Rafferty et al (2005) observed that many clients are affected mentally, not because of the disease but because of society's rejection of them. This study also observed that a few of the women interviewed were depressed due to the disease and did not disclose this to anyone as they felt ashamed. A 33-year-old woman often had suicidal thoughts because she had leprosy.

A person affected by leprosy, who is frequently ashamed of his/her appearance, is prone to self-exclusion. This can be explained by two factors: the association of the disease with certain behaviours condemned by society, and people's morals and beliefs. The people who are affected can face discrimination, but they can also self-exclude themselves due to the fear of being the subject of stigmatisation once they reveal their condition (Castro, 2016). In this study also, some women were afraid of the community, that people would criticise and isolate them, and even their family members would be separated from their village. In considering marriage prospects, a 53-year-old woman reported that she would prefer her son to get a bride from a family with a history of leprosy, for fear of stigma and discrimination by other families.

Proper footwear along with regular self-care can prevent the development of foot ulcers and ulcer-related complications (Berendt and Lipsky, 2004). Unfortunately, due to fear, self-stigma, experiences of societal stigma and stigmatisation from family members, some women were not able to properly manage self-care and wear protective footwear for their anaesthetic foot in order to prevent deformity. A study from India (Lal et al, 2015) reported that the use of microcellular rubber (MCR) footwear declined during social occasions due to stigma. This study also found that a few of the women were not using the protective footwear (MCR) due to stigma.

People affected by leprosy feared telling their own family about the disease, due to fear of stigma, isolation and social exclusion (Garbin et al, 2015). Moreover, the major cause for the late diagnosis of leprosy in women is the fear of stigma and being ostracized by their family and community (Lepra, 2018). Studies from Nepal reported that husbands left their wives affected by leprosy and also sent their wives away to their parents' house (van 'tNoordende et al, 2016). This study also observed that some women felt afraid to disclose their health status even to their family members, while some limited disclosure to their parents and some to their husbands, since they thought that the disease would create serious problems like isolation, divorce, and discrimination.

It is well known that leprosy is an ancient disease surrounded by lots of myths and misconceptions (The Leprosy Mission Trust India, 2018). The beliefs and perceptions about leprosy were found to be the prominent cause of stigma (Try, 2006). In India, in addition to the fear of infection, false beliefs about leprosy, ignorance about the disease and lower socio-economic status were associated with stigma in leprosy (Nagaraja et al, 2011). Also, leprosy has been considered to be an infliction of wrong-doings and sins (Sinha et al, 2010). This study also observed that women still retain the old beliefs and myths about leprosy.

Women can be triply disadvantaged with regard to health concerns, due to their gender, potential disabilities and the societal stigma which arises from them (Griffey, 2015). If a mother has leprosy, the health and well-being of the whole family can be affected. Fear of passing on the disease can prevent emotional closeness and bonding with her children and also reduce positive health behaviour (Rafferty, 2005). Discriminative attitudes are more common in joint families than nuclear families (Kaur and Ramesh, 1994). Although many people get support from their families, the disease has definite psychological effects (Kaur and Ramesh, 1994). The attitude of the husband and family members even after cure, influences the psychological milieu of the client from immediately getting the diagnosis of the disease (Kaur and Ramesh, 1994).

The potential for stigma and discrimination against persons affected by leprosy continues to challenge early detection and successful completion of treatment. Many people affected with leprosy continue to experience social exclusion, depression, and loss of income and often it is extended to their families also (WHO, 2018). Over the years, with the introduction of MDT and IEC campaigns in India, the stigma and discrimination against persons affected with leprosy is gradually reducing. The National Leprosy Eradication Programme (NLEP)

India has continuously made innovative interventions to eliminate the stigma and discrimination faced by the people affected by leprosy (NLEP India, 2018) in order to fully integrate these people in society.

CONCLUSION

This study concludes that women affected by leprosy still fear the disclosure of the disease. They do not want to disclose their health status to their family and neighbours in order to avoid negative consequences such as the stigma and discrimination attached to the disease. This study shows that the negative behaviour of the community towards women affected by leprosy persists, which subsequently means that women frequently try to conceal their disease from fear of these negative attitudes and practices. Even when there was no problem in the community, many women interviewed choose to limit themselves in exposing freely their health condition. In addition, women were apprehensive about their marriages and jobs, and commonly reported psychosocial issues like depression. Continued education about the disease and its transmission is very essential to spread awareness among the people affected by leprosy, their families, and in the community. It should be a continuous process in order to reduce or remove the stigma and discrimination faced by women in particular. Periodical counselling for women affected with leprosy and their family members would help to improve the psychosocial well-being of these women.

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